

ADVANCE DIRECTIVES

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Advance directives were created in response to increasing medical technology. An **Advance health care directive**, also known as **living will**, **personal directive**, **advance directive**, or **advance decision**, are instructions given by individuals specifying what actions should be taken for their health in the event that they are no longer able to make decisions due to illness or incapacity, and appoints a person to make such decisions on their behalf. The living will is the oldest form of advance directive. A living will is one form of advance directive, leaving instructions for treatment. Another form authorizes a specific type of power of attorney or health care proxy, where someone is appointed by the individual to make decisions on their behalf when they are incapacitated. People may also have a combination of both. One example of a combination document is the Five Wishes advance directive in the United States. To learn more about the Five Wishes document you can visit the website www.agingwithdignity.org.

Today I will offer you 5 steps, as a guideline.

Step One – Asking the right questions and determining the right answers. When it's time to determine what your wishes are for managing the end of your life, here are the questions you'll need to address, and resources for determining your own answers.

1. Who do you want to designate to make medical decisions on your behalf when you are unable to make them? This person, called your healthcare proxy or medical power-of-attorney, is the person who you know will make decisions the way you want them made, and who can most easily stand at your bedside, if necessary. Your proxy will need to make decisions for you if you are in a coma or suffer another debilitating event, and can't speak. In addition to your primary representative, you'll want to designate who your second choice representative should be.

2. What kind of medical treatment do you, or don't you, want to have? Should you be kept alive on a respirator (breathing machine) or with a tube that feeds you (nutrition) or provides fluids (hydration) to you artificially? Under what circumstances? If your breathing stops or your heart stops beating, do you want to be resuscitated? Under what circumstances? If you are in a great deal of pain, and

can't make clear decisions, knowing you'll be given high doses of pain-killing drugs, do you want that pain relieved? These are difficult questions and not easily answered. Often the answers come with caveats such as, "I don't want a feeding tube, UNLESS there is a good chance it's only temporary." Most resources suggest that the more specific the answers to these questions, the more difficult it is to determine whether the criteria are being met. You may have very strong feelings about whether you would be want to be kept alive, even if you knew the eventual outcome would be death. Or perhaps you're very clear about your feelings but don't know how they can be expressed on paper. That's why it's so important to discuss these kinds of thoughts and feelings with others whose opinions you value and trust. You may want to sit down with other loved ones, clergy, a trusted medical adviser or even an attorney to be sure you are thinking through all the questions and potential positives and pitfalls to the answers.

3. As you reach the end of your life, do you want to die at home? Or is hospice care, including palliative an option for you? Many years ago, most people died at home because that was their only option. As hospitals become more a part of end-of-life patient care, people began fearing death in a hospital, perceived to be too sterile and impersonal. They would implore their families to let them die at home. In more recent years, a movement toward hospice and palliative care has grown. Hospice is both a facility and an attitude toward end-of-life care, offering patients and their families death with dignity, respect, pain control and comfort. The difference between hospitals and hospice is the difference between curative care and palliative care. Curative care is treatment with the intent to improve symptoms, while palliative care is aimed at reducing pain and discomfort with the intent to reduce a patient's suffering. Many hospitals and nursing homes offer hospice and palliative care services within their facilities. Most insurance policies, plus Medicare and Medicaid pay all or part of the treatment costs for patients receiving these services.

4. Once you die, are you willing or unwilling to donate your organs or tissues to other people whose quality of life will be improved by their use? Would you be willing, or unwilling, to donate your entire body to be studied in an academic medical university by researchers, doctors and students? Many people reduce their stress about the thought of dying when they consider the possibility of improving the lives of others through organ donation or whole body donation. Helping a blind person see, providing a liver to someone with disease, or donating skin to a child who has been burned is a selfless gift that goes beyond the donor's own life. Others object to the prospect of donation, sometimes due to religious reasons, and sometimes "just because." Questions about the point of death, when

and how it is determined, give rise to questions about organ removal, called "harvesting," and at what point in the declaration of death that takes place.

Step Two - Making sure your end-of-life wishes are carried out requires you develop written documentation. You'll need to consider documents like a living will, a durable power of attorney, and if you so choose, an order that will tell providers not to resuscitate you (called a DNR for "do not resuscitate".) Legal requirements and the names for documents vary from state to state. Some require notarized signatures. Some require witnesses who are not family members to sign the documents. Written documentation is a protection for you. The stricter the proof required that your documents are authentic, the better protected you are. Having signatures from people outside your family, including professionals, makes it much more difficult for someone to act outside your wishes. Those requirements protect the loved one you designate as your proxy, too. With all the required signatures in place, the person who is assigned to carry out your wishes has a clear cut set of rules to follow. The professionals involved will not be able to question your intent when the proof is in place. If you live in more than one state, like those who live north in the summer and south in the winter, you will need to be sure the appropriate documents are written and signed for each location. Also, be sure to date the documents you develop so that if you decide to make changes later, your most current wishes will be enforced.

What Documents Record Advance Directives Decisions? As mentioned, each state recognizes end-of-life documents differently. This is also true for the names assigned to those documents. The following are the titles heard most often, what they record, and what their intent is:

Healthcare Proxy - A proxy is both a document and a person. Choosing someone to make medical decisions on your behalf means you have chosen that person as your proxy. It's always wise to choose a secondary proxy, too, because your primary proxy may predecease you, or may be unable to carry out your wishes for some other reason. When proxy is used to describe a document, it actually refers to a Durable Power of Attorney (DPOA) which is a legal document, with signatures required, that describes the same information found in a living will (see below.) It may also be referred to as a Medical Power of Attorney.

Living Will - When faced with a terminal illness, a patient can create a living will that will spell out her wishes as she faces the end of life. A living will answers questions such as whether the patient wants to be fed through a feeding tube (nutrition or hydration), whether breathing should be assisted by a machine (respirator), or whether the patient's heart should be started should he go into cardiac arrest. A living will is the document that helps the patient weigh the quantity of his life against what it will take to continue his life.

DNR - This is the acronym for a Do Not Resuscitate order. A DNR spells out the conditions under which you prefer not to be resuscitated by CPR (cardio pulmonary resuscitation), so that if your heart stops, you will not be revived.

Organ Donor Card - Many parts of the human body can be donated after death with the intent to improve the quality of life, and quantity of life for others. According to the US Department of Health and Human Services, each body can provide up to 50 donations of organs or tissues, including eyes, the heart, liver, stem cells, skin and others. For some of us, deciding to donate an organ or tissue is a simple decision. Others find the decision more difficult for a variety of reasons which may include religious beliefs. Each state has different laws about how your wish to donate may be recorded. For example, not all states recognize a signature on one's driver's license to be sufficient. You'll want to be sure to understand the requirements in your state.

What If Your Wishes Are Not Written in a Document? There's no question that formal, written advance directives are a much more defined outline of your wishes. But that does not mean that your wishes made orally, in conversation, will be ignored or dismissed. In most states, a conversation between you and someone you have not formally designated as a proxy, or with a healthcare professional, can be recorded by acceptable witnesses, and will be followed. For example, if you are in the hospital and you tell your spouse you do not want to be resuscitated, and the conversation is witnessed by your doctor or a nurse, then your wishes will be written down by one of those professionals, and will be respected. Regardless of whether your wishes are put into writing or not, making your family and loved ones aware of what those wishes are is very important.

Step Three - Advise those who might be at your bedside at the end of life about the decisions you have made. Those people may be your: proxy (and secondary proxy), spouse or partner, children, parents, siblings, healthcare providers, attorney, pastor, priest, rabbi or spiritual advisor, caregivers, close

friends who may be at your bedside. Some people have already accomplished this step while as those decisions were being made, and the documents prepared.

For example, asking permission of a healthcare proxy before designating that person's name in an advance care document would mean that the proxy knows about that choice. Using an attorney to draw up the written documents (which is not required, but can be helpful) would mean the attorney has already been advised of those wishes.

Step Four - Store the documents and notes you've made for the time when they become necessary. The documents need to be easily accessible, and readily available. That means you will not want to store them where they will be difficult to find, like in a safe deposit box or a home safe. Since they aren't meant to be secretive anyway, keeping them in an obvious place is your best choice. Consider the following as good ways to keep your advanced directives.

Hardcopies: Keep in a filing cabinet labeled with something obvious. Keep them with your will. Keep them with additional important papers, including contact phone numbers and addresses for others who need or wish to be notified. Provide copies to your primary care physician or attorney.

Electronic copies: Keep in a file folder on your computer, labeled. Email copies to your proxy and secondary proxy.

What If You Want to Make Changes? Your end-of-life wishes may change over time. It should not be difficult to update your written directives. Be sure to date every copy, and replace copies held or stored according to the list above. When the time comes, if more than one document exists and the instructions are different, the more current document will be enforced.

Step Five - Starting the Conversation - *Have you already had this conversation with your loved ones? How did you start the conversation? Will you share your conversation starter with others?* One of the most difficult conversations in our lifetimes may be the one that covers how those lifetimes might end. Here are some conversation starters for sharing and learning: What are your end of life wishes? And how do you share them with your loved ones? How can you be sure they will carry out your wishes if the time comes? What are their end of life wishes? And what will you choose for them if called upon to make those tough decisions? How

will you know what those choices are? And what if you aren't sure about your own choices? Starting the conversation may help you make those determinations. Take a look at these ideas and adjust them to fit your circumstances.

Setting the Stage - A difficult conversation such as one about end of life choices might be easiest in a group. When your family comes together at the holidays, or even with your book club or dinner group, use one of the suggestions below. Some safety or comfort is in numbers. It becomes more philosophical and less personal. You can move it into the more personal realm once the conversation has begun. If a glass of wine loosens up the conversation, so be it! Before you get started, make yourself familiar with the decisions that need to be made, and the possibilities for the ways life may be prolonged or pain controlled, plus the options for organ donation or death with dignity. Remember that having this conversation and later recording your choices may save you and your loved one a great deal of heartache, and perhaps even your family's savings.

Find An Example from Your Family - Think of a relative who died long enough ago that the emotion has passed, but the memories are still there. Ex. *“Does anyone know how Great Aunt Dorothy died? No one ever talked about it then. I wonder if she died at home?”* or *“Do you remember Dad's cousin Harold who was in a coma for a month? I wonder if there was any argument about keeping him on that ventilator? It must have cost them a fortune to keep him alive, but maybe that's what he wanted?”*

Find an Example from the News - These examples are, sadly, plentiful and much less personal than choosing someone in your own family to discuss. Ex. *“How sad for the parents of that child that drowned. But how generous they were to donate her organs.”* *“Remember Terry Shiavo, the woman who was in a coma for years? I would never want that to happen. If the doctors tell you there's little hope for me, let me go!”*

Use a Conversation Prop - Many books and movies deal with end of life, which are good stories. Discuss one of these books or movies with whoever will make the decisions for you. After, use the story to springboard your own discussion about end of life wishes. Ex. *“Tuesdays With Morrie”*, *“The Notebook”* or *“The Five People You Meet in Heaven”*

Blame Someone Else for the Necessity of the Conversation - Sometimes it's easier just to offset the blame. Ex. *“Pastor Jones raised the question about what*

choices we would make at the ends of our lives, and I realized I don't know what your choices would be.... any thoughts?" Or "My attorney wants me to fill out proxy paperwork. Will you help me?

Once you begin the conversation, it will take on a life of its own. It may get lively, and it may even take directions you don't expect. Make sure you keep it on topic as long as is necessary to get the answers you need, or to make the points you want to make. Then, follow up by filling out the necessary paperwork and advance directives.

Resources: Aging With Dignity, Trisha Torrey, Wikipedia

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